

TIPS FOR RESEARCHERS INVOLVING UNPAID CARERS IN HEALTH AND CARE RESEARCH

Co-produced with carers and researchers

A note on language: It's important to remember that unpaid carers may not identify with the term "carer" so be mindful of the language used when engaging and communicating with them



Be flexible

Ask carers about their needs and try to accommodate them. Let them know if you can't accommodate certain needs and explain why. Also, understand that their involvement may not be guaranteed and may change at the last minute.



Factor in the physical and mental health needs of carers, plus the emotional costs of being involved in research

Sharing experiences can have an emotional impact, so there may need to be an offer of personal support, for example through carers organisations, providing links to other carers for peer support, providing support via your team or encouraging them to speak to someone in their personal network.



Plan and budget your involvement with carers and carers organisations

In addition to the normal costs associated with involvement, factor in costs specifically for carers, such as reimbursement for hiring additional carers or support workers during meetings (carer costs). Offer these carers costs so they don't need to ask.



Recognise that carers are people first

Carers have other interests, aspects to their lives and other commitments. Allow them the space to talk about themselves as people and take the time to get to know them on a personal level (if they wish to share this).



Keep carers updated and communicate the impact of their involvement

Carers are giving up their time for you. Plan communication that works best for them, give project updates (including any delays), ensure a feedback loop, and let them know the impact of their involvement.



Reduce the burden on carers

Carers are busy and research may not be their priority. Make processes simple and straightforward to avoid extra fatigue or disengagement. This includes payment and application processes.



Involve carers from beginning to end and at all stages

This will benefit your research by helping define the questions asked, advising you on how the study is run and developing meaningful outcomes. Carers can also help you evaluate and share your research results once the study is complete.



Carers often wear multiple hats

Carers have their own identity but may also be speaking on behalf of someone else, especially if that person lacks capacity. Be aware that reflecting another person's views can be tricky and may differ from the carer's personal views. Carers may also not be able to share specific details.



Carers need to be heard as a unique and valued part of service delivery

Services impact carers differently than the person(s) they care for and their views are just as important. Regularly communicate with them to show that you value their input.



Involve the right carers with relevant experience(s)

The relationship between the carer and the person they are caring for can vary depending on how they are related to that person. Think about what caring experience is important for your research and involve the right carers for your study.

#CarersInResearch

TIPS FOR CARERS TO GET AND STAY INVOLVED IN HEALTH AND CARE RESEARCH

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You have a voice

Know that sharing your views and experiences as a carer is important, valued, worthwhile and can make a difference.



Don't be afraid to ask

For help and support (including payments) and for what you need to be involved i.e. flexibility and what time commitment will be required.



It's ok to say no and it's ok to stop

Be mindful of your own capacity and limits. Don't feel pressured to over-extend yourself and to let people know if you need to step back.



Being involved in research is an opportunity to learn and develop

Take advantage of the chance to learn from others, enquire about available training, and reflect on the skills you have gained through your involvement. Consider ways you can continue to grow and develop in your role as a contributor.



Your own needs as a carer are important

Keep in mind your own needs as a carer, in addition to those of the person you care for, and make sure to ask for them to be taken into account.

#CarersInResearch